PARENTS OF CHILDREN WITH DISABILITIES BENEFIT FROM THE INTERNET FOR DEVELOPMENT, LEARNING AND CONNECTING

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ABSTRACT

Good Parenting! What it means and being prepared to do it is highly ambiguous in nature. Most parents-to-be want to be good parents and readily believe they are prepared to be good parents. That is until the baby arrives. With every birth comes an even distribution of positive and negative thoughts and emotions. In typically developing pregnancies and problem-free births the positive features are more prominent but this can change dramatically when parents are faced with discovering their unborn fetus or their child has a genetic abnormality, birth defect, disability, or chronic illness. Children with serious medical illnesses and chronic disabilities endure many obstacles as they persist through cognitive, social, and emotional developmental milestones. Technology can function as a tool to help accomplish crucial tasks of parenthood by promoting many aspects of child development (Blanchard, 1997). However, a gap in the literature persists when it comes to how new technologies can provide critical information and support for parenting children with disabilities or chronic illnesses. The focus of this paper is on how new technologies can supplement and provide a type of co-parenting support for parents of children with disabilities or chronic illnesses.

Keywords: Technologies, Parenting Children with illness or Disability.

INTRODUCTION

Parenting can be defined as "the care and nurturing of offspring between conception and independence" (Bjorklund, Yunger, & Pellegrini, 2002; p. 3). Children with serious medical illnesses and chronic disabilities endure many obstacles as they persist through cognitive, social, and emotional developmental milestones. **Parents** question their child's full potential, what will they be able to do, how will this affect their life, what about their friends, and what about school, how will this impact their education? Along with the child's illness or disability, parents are exposed to overwhelming new technologies, and these days children embrace new technologies with much more ease than most adults. The purpose of this article is to discuss how information, communication, and media technologies can and do assist parents and their children during the challenges of sickness to achieve cognitive, social, and emotional development for their child as they all adjust to the illness or disability. The authors' goal is to demonstrate how the challenges that seriously ill or disabled children and their parents encounter may be managed with less effort and stress given advances in information, communication, and media technologies. The article has two main sections: (i) technology and parenting the child with disabilities; and (ii) technology and the preschool child with a disability. The authors will identify how parents can scaffold their child's development and learning through the use of new technologies and resources; and how parents can develop an abundance of knowledge and tools that can make this time filled with more happiness and less stress and anxiety.

Literature

Parenting a child with a disability has specific challenges and present trying experiences. Care-taking responsibilities typically escalate significantly beyond that of what was initially expected. Government policies (USA) such as, the Individuals with Disabilities Educational Improvement Act, 2004 (IDEA) are designed to assist parents in meeting the needs of their child. According to the National Association for the Education of Young

Children (NAEYC), families that include a child with a disability or serious illness are often unable to find appropriately trained professional child care programs that are able to meet the specialized needs of their child. Forty-five percent of mothers who have a child with a disability are unable to return to competitive employment. It has also been estimated that a caretaker of a child with a disability spend 86% of their day within three feet of their child (Heiman, 2002). Despite more recent government policies that have increased the funds allocated for infants and toddlers to improve early intervention services for children aged birth through three, the need for quality professional help remains a necessity as the majority of the responsibilities continue to fall on the shoulders of predominantly untrained and socially isolated parents.

The social innovation that has arguably most impacted every facet of life - including parenting - is technology. One cannot examine hardly any occupation, leisure activity, or even social relationships without considering the impact of the "digital age." To try to do so would decontextualize many activities to the point that they would no longer retain a recognizable form. Technology has and continues to revolutionize the ways in which parents obtain support and information as well as the ways in which children with disabilities are supported. For parents of these children, the rapid changes in technology can bring current support while offering future hope, that their child will lead a full and happy life. Diagnosing illnesses and abnormalities using sound wave technology has advanced from Standard Ultrasound to Dynamic 3-D Ultrasounds (Figure 1).

The first encounter between the unborn child and the expectant parents is facilitated by technology; whether via a urine test or an ultrasound. Several studies have shown that the parents' first view of the fetus on the ultrasound



Figure 1. Standard Ultrasound (Left) & Dynamic 3-D Ultrasound (Right)

screen helps build feelings of attachment between the parent and the future child (Ji, Pretorius, Newton, Uyan, Hull, Hollenbach, & Nelson, 2005; Bjorklund, Yunger, & Pellegrini, 2002). The ultrasound image (Left) of a 12 week old unborn baby; this is the image that parents get to see. From this picture expectant parents can find out the sex of their unborn child. It is not at all uncommon for the parents-to-be to show the ultrasound picture to family and friend or post it on Facebook to inform others about the new family member. Historically it was the birth of the baby that marked a new family member; however today expectant parents choose names, design rooms, buy clothes and furniture; and even begin to plan futures based on the results of an ultrasound. Further, more advanced ULTRASOUND technology (Right) can provide physicians information about the health and well-being of unborn babies. Ultrasound sophistication provides many layers of diagnostic tools for physicians and parents. Advanced, Doppler, 3-D, 4-D, and Dynamic 3-D Ultrasounds are used to detect or aid in the detection of abnormalities and conditions related to difficult pregnancy. Ultrasounds are usually combined with other tests, such as triple tests, amniocentesis, or chorionic villus sampling, to validate a diagnosis. Measuring levels of specific substances in the blood, known as markers, can help identify women with an increased risk of problems, such as having a baby with a brain or spinal cord defect, Down syndrome, other chromosomal abnormalities, and some rarer genetic disorders.

In the words of one expectant mother, "just seeing the baby...it was just like, 'Oh my gosh, there's really a baby in there.' And [my husband] was just like, 'Oh my God!'...We brought the tape home that night and watched it over and over" (Williams & Umberson, 1999; p. 157). Parents reported that this first visual contact with the child helped them to feel as if the pregnancy were more real, experience a closer relationship with the child, and trust that the baby was healthy. First time mothers report turning to the internet for advice when their child exhibits acute symptoms, when the doctor's office is not accessible, or when they need to make decisions about whether or not a visit to the emergency room is merited (Bernhardt & Felter, 2003). Beyond health information, parents also access the

internet to gather information about normative parenting concerns, such as behavior issues, child development, parenting practices, and education (Bernhardt & Felter, 2003).

Unfortunately, for some parents that first technological contact, the ultrasound, echocardiogram, or amniocentesis, delivers unthinkable news – that the child in utero is not healthy or "normal," and that they may have a genetic condition, disability, or congenital anomaly. When the news is delivered, parents may feel anger, anxiety, sadness, or even grief (Letuhner, Bolger, Frommelt, & Nelson, 2003). One mother whose daughter had been prenatally diagnosed with Down Syndrome shared; "I felt as if the whole world had fallen on me. I didn't understand how this could be happening to me, and I thought, how will I return home?" (Helm, Miranda, &Chedd, 1998; p. 57).

In the two scenarios mentioned above, the result and subsequent reaction to the ultrasound is different but the role of parents does not go away. The needs and demands of the parent and the child will be partially but not entirely different. As the child grows and develops parents will need information and knowledge of appropriate milestones, behaviors, techniques, and practices to be the best parent they can be. Parents will need social and emotional support; and they will seek ideas and other resources. Fundamentally the parent will seek different information but the goal is consistently to care for and nurture their child. They will turn to computers, digital devices, and the internet for parenting information, educational and developmental goals, support, and entertainment.

Early detection and diagnosis of a disability leaves parents feeling alone and many turn first, to the World Wide Web (Internet) for information, communication, and support. The ease and availability (or lack thereof) of the information and support they need can significantly impact their ability to make quality decisions regarding the future care and nurturing they provide for their child in the present and future. According to Pew (2007), 93% of youth in America use the internet on a daily basis, and 75% of American households are connected to internet services. In altering the home environment, technology likewise transforms the

interactions and dynamics occurring in the home life of the family. In fact, some contend that new information technologies provide opportunities for parents and children to continually negotiate the parent-child relationship, to redefine the roles of parent, child, and family (Davis et al., 2008). Technology influences parenting practices, child development, and parent-child relationships, which in turn shapes how the family interacts with society.

Although most parents and children utilize technology on a daily basis, it may be used in a variety of ways to serve varying needs. In the case of parents of typically developing children, the internet, computer, game systems, and the internet offer family entertainment, social connections, and efficient ways to accomplish the daily tasks of living. Technology is functions as a tool to help accomplish crucial tasks of parenthood by promoting many aspects of child development (Blanchard, 1997). However, for the parents of a child with disabilities or a chronic illness, technology may mean the following: (i) accurate diagnoses, (ii) cutting edge treatments, (iii) social and emotional support, (iv) making critical decisions about their child's growth and developmentas much as possible in the face of medical challenges. Although the experiences of parents of typically developing children and those with disabilities or chronic illnesses may differ greatly across the family life span, one thing that remains consistent across groups is that both groups actively utilize technology. This paper will explore the various ways in which technology impacts dyads between parents and children with disabilities.

Technology and Parenting the Child with a Disability

For some parents technology brings an unanticipated crashing blow – that their child has a disability or other complex medical and social needs. It has been estimated that 18-44% of children living in developed countries across the globe have a special healthcare need (Van Der Lee, Mokkink, Grootenhuis, Heymans, &Offringa, 2007). Of these children, 1 in every 1,000 has a disability that causes them to be dependent upon some sort of technology for survival (Feudtner, Villareale, Morray, Sharp, Hays, & Neff, 2005). More specifically, in 2005, over

30,000 preschool children were identified as having an autism spectrum disorder (Office of Special Education Programs, 2005). Thus many parents each year will discover that they will be raising a child with one or more disabilities.

The advent in medical technology have helped to detect disabilities sooner and more efficiently, these innovations have also allowed children with disabilities or congenital anomalies to enjoy longer life spans and more normative participation in daily life and society (Norris & Hoyer, 1992). Children who previously would not have survived into adolescence can now become middle-aged adults, and the nonverbal, severely disabled child is not institutionalized, but is given devices that allow them to socialize with peers and participate in the classroom (Nkabinde, 2008). Because of these advances, many families are now living everyday with a child with disability and the face of parenting a child with disabilitieshas been revolutionized.

During the pregnancy period, a diagnosis can be made through ultrasound, amniocentesis, or other imaging or genetic testing procedures – such as in the case of Down syndrome, various genetic conditions, and large physical disabilities or malformations (Helm et al., 1998; Ji et al., 2005). In other cases, such as with autism spectrum disorders, pervasive developmental delays, and cerebral palsy, diagnosis occurs within the first few years of life as the child fails to meet or is delayed in meeting typical developmental milestones (Lainhart, 1999). No matter when the child is diagnosed, diagnosis delivery is difficult for parents and can even initiate feelings typically associated with grief reactions (Letuhner, Bolger, Frommelt, & Nelson, 2003; Pianta, Egeland, & Hyatt, 1986). retrospectively asked about their experiences with receiving a diagnosis of disability for their child, parents have described this time as a key milestone in their lives (Rahi, Manaras, Tuomainen, & Hundt, 2004). Kearney and Griffin (2001) also found that parents describe the diagnosis as a moment of discovering the child's changed future.

As emotions and shock intermingle at the moment of diagnosis, parents are given a wealth of facts and advice concerning the newly named disability and are expected to retain, synthesize, and act upon this immediate information (Kearney & Griffin, 2001; McWilliam& Scott, 2001; Milner, Bungay, Jellinek, & Hall, 1996; Rahi et al., 2004). Admittedly, some parents are emotionally paralyzed, so they refrain from asking questions of the medical team and instead turn later to the Internet to seek answers in laymen's terms (Skinner & Schaffer, 2006). On the other hand, some describe feeling powerless due to the overwhelming presence of medical staff and equipment, such as parents who receive difficult diagnoses in the neonatal intensive care unit (Norris & Consistently, parents of children with Hoyer, 1992). disabilities report the most pressing need at diagnosis is for information: information about the condition, the availability and efficacy of treatments, long-term prognosis, and psychosocial coping resources (Heiman, 2002). For example, parents of children who are blind report that their greatest information needs at diagnosis pertained to information about social and educational services as well as family support resources (Rahi et al., 2004). But, these information needs are not always clearly met in the medical setting. Heiman (2002) found that 46.8% of parents of children with disabilities stated that they received inadequate information about social, educational, and psychological services and resources.

Although technology is often responsible for rendering the diagnosis, it is technology as well that many parents of children with disabilities turn to in this moment of informational, emotional, and social need. Even parents of typically developing children often seek health-related information from the internet, with one study in Australia finding that 52% of parents who presented to the pediatric emergency room had consulted health information on the internet before seeking treatment for their child (Khoo, Bolt, Babl, Jury, & Goldman, 2008). The use of the Web for medical information has been seen to increase across the globe in recent years (Baker, Wagner, Singer, & Bundorf, 2003). At the same time, there have been health information seeking differences between cultural and ethnic groups – for example, Spooner and Rainie (2001) reported that African Americans are more likely to utilize the internet for this purpose as compared to Caucasian Americans. Recognizing this interest in internet-acquired health data, clinicians and mental health professionals

have utilized internet sites and computer programs to deliver family intervention services (Gringas, Santosh, & Baird, 2006; Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009; Wade, Carey, & Wolfe, 2006). On the contrary, other medical specialists and service providers have warned against the gross inaccuracies and potentially misleading "facts" that may lurk across the World Wide Web (Wright, Williams, & Partridge, 1999). The fact remains, nevertheless, that parents of children with disabilities are turning to technology not only for information but also for support in difficult times of health crisis.

Technology and Health Information

According to Palermo and colleagues (2009), some of the benefits of posting information on the internet are the flexibility, ease with which information can be updated, and the potential to disseminate this information to a larger audience. Zevenbergen (2008) states, the immediate response capabilities of the internet have created a culture of instant feedback in the dominant culture. But for the parent of a child who has just been diagnosed with a disability, a parent who feels as if they had just entered "a world in which they had no experience and knowledge...and no signposts or maps," instant information is of the utmost importance and is actively sought via the internet (Kearney & Griffin, 2001; p. 587).

First and foremost, parents of children diagnosed with disabilities describe turning to the World Wide Web for information about the child's condition. In a study with parents of children undergoing cardiac surgery for congenital heart diseases, it was found that 58% of respondents had sought information on the internet pertaining to their child's cardiac diagnosis; of these same respondents, 95% rated the information that they had found on the internet to be "very helpful" to their understanding of their child's diagnosis (Ikemba, Kozinetz, Feltes, Fraser, McKenzie, Shah...et al., 2002). Parents of children with genetic disorders also report gathering information about their child's condition on the internet to either prepare for genetic clinic visits or to better understand and interpret the information they had received during the clinic appointment (Christian, Kieffer, & Leonard, 2001).

Porter and Edirippulige (2007) investigated the internet health information search strategies of parents of deaf children to learn more about the types of information they sought and the sites they visited along the way. Parents shared that they had looked for internet information related to hearing loss, hearing aids, cochlear implants, and alternative therapies. According to 87% of these respondents, the preferred starting point on their informational quest was a generic search engine. Next, parents visited sites that they felt were knowledgeable about hearing loss or those that had been recommended to them by clinicians, family members, friends, or the national publication on hearing loss (Porter & Edirippulige, 2007).

Beyond gathering information about the disability itself, parents also utilize the internet to obtain information about various treatments for their child's condition. Tsai, Tsai & Shyu (2008) examined mothers of preschool children with autism in Taiwan and found that seeking treatment information was a recurring theme; this was defined as "the actions mothers took to explore possible treatment methods or training programs to improve their child's behaviors and autism symptoms" (p. 1802). These findings are identical to McWilliam and Scott (2001) who explored families of children having all types of disabilities and special health care needs. Skinner and Schaffer (2006) also reported that parents of children with genetic diagnoses used the internet to conduct searches on treatment advances and stay up to date on the research addressing the child's illness and treatment. Furthermore, 10% of these parents remained actively involved in online parent groups after conducting these informational searches.

Other sought-after information is long-term trajectories or prognoses for the disability. Once parents have identified what they would consider to be the best possible treatments, they desire to know the likely outcomes that those treatment combinations will produce, and the possibilities that they may open up for their child down the road. Farmer, Marien, Clark, Sherman, & Selva(2004) completed a family needs survey, and it was found that they most frequently reported desiring information on ways

that they could help promote their child's health and development over time, and information about the types of services available for addressing their child's needs. Along with gaining information about services currently available, these mothers were also looking to the future, and reported needing information about the services that their child may need as they continue to grow and age (Farmer et al., 2004).

A concern about future needs and possibilities might explain why many parents of young children with disabilities are especially interested in gaining information about educational services. Parents of children who are deaf report seeking information about educational possibilities shortly after diagnosis, and rank educational options as the second most popular internet search topic related to their child's condition (DesGeorge, 2003; Porter & Edirippulige, 2007), as do parents of children with autism and other developmental disabilities (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008).

Social resources and programs that support social and emotional adjustment to schooling, as well as, how these needs are supported within particular schools are of importance to parents (Heiman, 2002). Again, parents turn to the internet to obtain information to explore the pros and cons of various schools and the methods adopted by the school. This may mean searching for inclusive or special education preschools, locating service providers who work within these schools, or gaining information about Individualized Education Plans (IEPs) or the Individuals with Disabilities Education Act (IDEA). But, this task especially seems to be easier said than done.

In a large national study of preschool children with autism and their parents, investigators discovered that it took families an average of 76.9 days, or roughly 2.5 months, from the time they started searching until the most appropriate services were located (Bitterman et al., 2008). For parents of children with other disabilities, this time frame was approximately one week longer with an average time span of 83.8 days. Furthermore, 22% of parents of children with autism and 12% of parents of children with other disabilities reported that "it took a lot of effort" to locate these educational services for their child (Bitterman et al.,

2008). Furthermore, parents of children with a range of disabilities have shared that they feel there are "not enough after-school recreational opportunities or services for children with developmental disabilities" (Heiman, 2002; p. 165). Overall, parents of children with disabilities express that it is often difficult to navigate and negotiate the wealth of medical and educational information that exists – even with the speed of the internet – in order to access those services that will be of most benefit to their child (King, Cathers, King, & Rosenbaum, 2001).

In the case of preschool children with autism, Bitterman et al. (2008) found that 87% received speech therapy services, 67.5% received occupational therapy, 45.6% participated in behavior management programs, 42.7% were given assistance with learning strategies and study skills, and 38.2% had a case manager or service coordinator working with their family. Interestingly, they also found that children with autism, when compared to children with other disabilitiesin their sample, had higher rates of service utilization. However, this high amount of service provision and usage is not always the norm across communities and regions. In truth, many children with disabilities are placed on waiting lists until service providers become available as there simply are not enough specialists to meet the complex needs of this population (Gringas, Santosh, & Baird, 2006). In addition, there can sometimes be subtle nuances between the roles of various providers, making it more difficult for families to locate qualified professionals to address each need (Hustad, Keppner, Schanz, & Berg, 2008). Furthermore, limitations due to finances or insurance coverage can further limit access to needed service providers. As these complications cannot always be foreseen, parents may once again turn to technology to locate available providers that can best meet the individual needs and goals of their child in a financially feasible way.

As the condition grows to be understood by the parent, as treatment is begun, and as services are acquisitioned, parents of children with disabilities begin to focus on some of the same issues facing parents of typically developing children – behavior management and general parenting. Blackburn and Read (2005) found that 72% of parents of

children with disabilities in their study had recently used the internet to obtain information about parenting their disabled child. Taiwanese mothers of children with autism viewed preparedness to manage their children's behaviors as an essential component of motherhood (Tsai et al., 2008). To improve their parenting skills in this domain, the mothers turned to professionals, teachers, and one another to learn strategies for rewarding positive behaviors and extinguishing those that were problematic (Tsai et al., 2008).

Seeking Support

The responsibilities that parents experience when raising a young child with a disability, involve high levels of stress, and low levels of social support. In the case of parents of children with autism, it has been shown that there are low levels of marital intimacy, significant levels of stress, and increased vulnerability to negative outcomes within this group (Montest & Halterman, 2007). Heiman (2002) further discussed some additional challenges that parents of children with disabilities face, such as increased incidence of parental health problems, feelings of restriction, and higher susceptibility to depression than parents of typically developing children.

It has been acknowledged that for parents of children who are disabled due to traumatic brain injury (TBI), adverse outcomes are likely with regards to mental health as injuryrelated burden persists for years (Wade, Taylor, Drotar, Stancin, & Yeates, 1998, 2002). Sturges (1998) argued that online interventions for these families help to avoid common barriers to mental health resources for parents such as lack of time, travel distance, and the lack of accessible and available service providers. Sturges (1998) reports that online treatments, when compared against traditional face-to-face therapy with a clinical professional, show that online treatment is generally at least as effective as more traditional approaches. Wade, Carey & Wolfe (2006) implemented an online family intervention program with parents of children who had suffered a traumatic brain injury and found two notable results: (i) parents who used the program reported decreased depression, anxiety, and psychological distress at follow-up when compared with parents who had not participated in the online program; and (ii) many parents of children with TBI reported that they would actually prefer online therapy rather than traditional face-to-face consultations. There is some skepticism regarding therapy in general; in the words of one mother of a child with special health care needs, "most professionals are not going to tell you the down and dirty truth you are going to get from other parents who live this every day. Probably because they could never imagine what it's like" (Baum, 2004; p.386). It seems that professional advice is at times treated with a grain of suspicion, as parents may perceive a disconnect between the professional offering services and the actual experiences that the parent encounters on a daily basis while caring for their child.

Multiple forums exist on the World Wide Web for parents to gain access to this type of parenting support. With over 50% of American households owning computers with internet connectivity, online social and emotional support communities have blossomed for all kinds of special interest groups, for adults and for children, for a variety of purposes (U.S. Department of Commerce, 2002). A largescale internet survey of parents of children with special health care needs found that there is a stifling need for continued online support, with 90% of parents endorsing participating in online groups of this kind (Baum, 2004). According to Birch (1998), there are four different types of social support that individuals can provide or receive. First there is emotional support, which is the express of sympathy, listening to their concerns, and remaining available to their needs. Second, informational support is just that – the sharing of information or informing others of ways to obtain requested information. Third, material support refers to monetary and material goods or physically assisting someone. Fourth, appraisal support is providing praise, reassurance, or affirmation to another individual. Zaidman-Zait & Jamieson (2004) found that these support protocols positively influence parent's coping processes.

To connect with other families and gain emotional support, then, many parents turn to the internet. Some utilize personal blogs to share their feelings, communicate with others, write about their experiences, and keep family and friends up to date on current happenings in the home. Others use email listserves through foundations and

organizations to connect with similar parents of other children with disabilities so that they can gain support from someone who "knows what it's like." Some of these organizations also provide bulletin boards and chat rooms for this purpose, and also to facilitate the exchange of needed information between clinicians, scientists, and parents with one another.

Email groups, chat rooms, bulletin boards, blogs, and online communities, however, are just a few of the many ways in which parents of children with disabilities access support from other parents. In a study of mothers of children with autism using an email group, content analysis revealed that mothers sent messages to one another containing themes relating to searching for meaning, adjusting to changes, providing support and encouragement, and narratives in which the mothers shared their experiences (Huws, Jones, & Ingledew, 2001). Jones and Lewis (2001) examined an internet discussion group for parents of persons with Down Syndrome and found that parents used the group to share information on medical issues, treatments, services, policies, and stressors of everyday living. Furthermore, parents indicated that using the group helped them to better gather and exchange information, share their feelings and opinions, and get advice and support from one another (Jones & Lewis, 2001). For mothers of children who had been prenatally diagnosed with Down Syndrome, talking with other parents of children with Down Syndrome was reported to be the single most source of information and support and "the most important connection they had made during the prenatal period" (Helm et al., 1998; p. 57). Additionally, when these mothers were asked what advice they would give to future mothers in the same situation, five of the ten recommendations they offered revolved around seeking out information and other parents of children with Down Syndrome. This advice speaks to the value and importance of parent-to-parent support (Helm et al., 1998). Part of the appeal of on-line support groups may be in the capacity of the internet to connect users to multiple types of sources and information at once; for parents who have identified the utter importance of information on a gamut of factors related to their child and his or her disability,

internet support groups appear to be a service well matched to the needs and concerns of this subgroup (Rice, 2001). This goodness of fit between need and provision, along with the efficacy and efficiency advantages that technology may hold over face-to-face support groups or therapies, may account for the many benefits that parents of children with disabilities perceive and report from using online support groups (Brotherson & Goldstein, 1992). According to a group of parents of children with special healthcare needs who had utilized an internet support group expressed the belief that participating in the group helped to improve the relationship between themselves and their child (Baum, 2004). It appears that the intrapersonal benefits that parents reap from participating in online support groups also carries benefit for interactions between the parent and the child – and the converse is true as well. Technology disseminates information, offers access to service providers, supports the educational and developmental concerns of parents, and connects caregivers with one another to give much needed social and emotional support. Parents have company in dealing with the illness and disability of their child; however the child is impacted by technology as well. The next section discusses the impact of technology on preschool children who are faced with a disability.

Technology and the Preschool Child with a Disability

For the young child with the disability, life can be quite different from that of their peers. First, opportunities to interact with the environment and others may be impaired due to motor, cognitive, social, or language deficits; in addition, it has also been shown that family dynamics are riddled with disability-related stressors thereby altering the opportunities for interaction available to the child even within the context of the home. All of these factors combined place children with disabilities at secondary risk for secondary issues such as cognitive, spatial-perceptual, and social-emotional deficits (Hansen, 2008). In the words of Heiman (2002), "a child's disability is a triadic experience, involving three way interactions among the child who experiences the dysfunction, the family that is affected by it, and the external environment where the disability is

manifested" (p. 160). Developments in technology, however, have been able to greatly increase and improve the child with disability's quality of life, developmental engagements and social interactions through the dispersion of assistive technology.

Assistive technology refers to "any item, piece of equipment, or product system, whether acquired commercially of off the shelf, modified, or customized that is used to increase, maintain, or improve the functional capabilities of a child with a disability" (IDEA, 2004). Based on the level of technology that they involve, assistive devices are termed either low- or high-tech. Low-tech devices refer to readily available items that are used by all children that have been slightly modified or adapted to fit the needs and capabilities of the child with a disability. Some examples of low-tech devices would include bulbhandled adaptive paintbrushes and eating utensils, cars, toys, alternative touch screens or trackballs for computers instead of mousepads, and Velcro – which can quickly adapt many items to the child's needs when in a bind (Judge et al., 2010; Shih & Shih, 2010). High-tech devices denote those that are specialized, complex, and outside the realm of typical use. These may include alternative and augmentative communication devices, or "speechtalkers," electronic switches for adapting toys and other items, power mobility wheelchairs, and computerized items (Campbell, Milbourne, Dugan & Wilcox, 2006; Floyd, Canter, Jeffs, & Judge, 2008).

Using both low- and high-tech assistive technology methods and products, young children can more often and more easily participate in the normative activities of their peers, and can continue to grow and develop more than may have been possible before the invention of these technologies (Campbell, 2004). However, assistive technology skeptics have suggested that devices are best for use with children who are school-aged and can best manipulate and care for the devices. But, this claim is unfounded it seems when the literature on assistive technology and young children is inspected. According to the National Center for Education Statistics (2005), 93% of children in nursery school to twelfth grade used computers regularly and 59% browsed the internet. When broken

down by age, 66% of children who were of preschool age were found to regularly interact with computers and computer related technology (National Center for Education Statistics, 2005).

Zevenbergen (2008) found that preschool aged participants could also actively demonstrate several skills when it came to computers in their homes, such as playing educational games, accessing the internet, and playing non-educational games. In addition, they could turn the computer on and off, use the mouse effectively, find letters or numbers on the keyboard, type letters, retrieve saved files, use drop-down menus, draw with digital drawing tools, utilize a touch pad, load and play CDs and DVDs, save files, operate the tool bar, print files and screen shots, and type words (Zevenbergen, 2008). This achievement of this technological skill set may be motivated by the observations that young children find interactive multimedia technology to be interesting and thus adapt easily to such programs (Min, 1996).

Although these were typically developing children, other studies have shown the technological prowess of even young children with disabilities. At least two studies have shown that children as young as 11 months to 39 months can learn to operate powered mobility chairs in home and in school when provided with adequate instruction (Jones, McEwen, & Hansen, 2003; Ragonesi, Chen, Agrawal, & Galloway, 2010). In addition, toddlers with severe sensory, motor, and cognitive disabilities are able to learn to use switches to control adaptive toys and other devices with practice (Sullivan & Lewis, 2000). Judge and colleagues also advocate for the introduction and use of assistive technology with young children, arguing that "assistive technology offers infants and toddlers with disabilities a set of tools to assist in achieving developmental goals while interacting with objects, materials, adults and other children in their environment" (Judge, Floyd & Wood-Fields, 2010; p. 84). In cases where the parent themselves is limited in their capacities to interact with the child with a disability, such as in the case of deaf children who are born to hearing parents, the early introduction of communicative technology is imperative for the child's development over the life span (Goldin-Meadows &

Mayberry, 2001). In this case, parents who are involved earlier in their child's communication develop are able to later communicate more effectively with the child and help to ensure that the child will continue to progress throughout childhood and adolescence (Huang, Smith & Spreen, 2008). For a description of a play-based assistive device for teaching sign language to parents and children, also see Huang and colleagues (2008). Without assistive technology, early childhood communication challenges have the potential to lead to isolation in social and educational settings and adverse developmental consequences (Romski & Sevcik, 2005; Sevccik, Romski & Adamson, 2004).

The goals of assistive technology, then, are to help children with disabilities to execute necessary daily activities and to achieve and exert functional independence while participating in activities; a secondary goal of assistive technology, some would say, is to help alleviate caregiver stress and burden as well (Ostensjo, 2009). Alternative and augmentative communication devices, in particular, have been shown to achieve these goals by fostering language development and socialization capabilities while also decreasing maladaptive behaviors (Hanline, Nunes, & Worthy, 2007). Bleck (1987) argued that because communication skills were such an area of concern for adults with disabilities, they should also be a priority for children whose communication is impaired due to disability. In addition, adaptive devices in general are a necessity for helping children to utilize and cultivate burgeoning skills across the cognitive, social, emotional, and language domains as well.

Although there are many benefits to assistive technology, there are also barriers to its use with children with disabilities. In a nationwide survey of early intervention specialists, it was found that 44% reported that either none or only a few of the children they served who could benefit from assistive technology were actually in possession of and able to use the devices (Wilcox, Guimond, Campbell & Moore, 2006). Sometimes the barrier is financial, other times the demand for assistive technologies far outweighs the supply. Occasionally, the issue at hand may be that the family has hired a professional to assess the child's technology who is

perhaps not as qualified as others; subtle nuances between provider roles can sometimes leave families frustrated with professionals who are not the proper experts or specialists in suggesting and providing assistive technology (Goldman, Lowman, Bryen & Lemanowicz, 2000; Hustad, Keppner, Schanz, & Berg, 2008). Parents may then take it upon themselves to research and locate AT devices, with one study reporting that parents spent more than 70% of the total time they dedicated to locating assistive technology on their own, without the aid of a professional (Wilcox, Dugan, Campbell & Guimond, 2006). In still other cases, the family is in possession of assistive technology in the home, but is not able to use it effectively due to lack of instruction of familiarity with the equipment (Long, Huang, Woodbridge, Woolverton & Mickel, 2003); this lack of familiarity can also hinder the use of assistive technology devices in the preschool classroom if the teacher is uncomfortable incorporating the items into school routines and activities.

To help boost the efficacy of assistive technology for children with disabilities and their families, many professionals have started to incorporate family centered care into their practice – the perspective that medical care and technologies recognize the primary of the family unit as a whole and provide care in ways that encourage the continued growth and development of the family (Hostler, 1991). Family centered technology, then, is "based on incorporating a parent and professionals in partnership for making decisions about the selection and use of assistive devices...the decisions should increase the likelihood of functional use of the technology in the child's natural environment" (Judge, 2002, p.77). Selections of equipment must be made in accordance with the young child's communicative needs, current communication capabilities, environments and routines in which the child will be expected to participate, and the level of technology that will best meet these needs (Hanline et al., 2007; Judge et al., 2010). At the same time, such technology will not succeed as highly without the support of the family, without a clear match between the family's preferences and needs and the devices they are given. Therefore, it is crucial that service providers work closely with families of children with disabilities to match the technology to the needs and

contexts of both the child and the family as a whole.

In addition to helping to improve domains of functioning and development, technology can also be enjoyable in itself, helping the child with disabilities to play and socialize with family members and classmates. As Zevenbergen (2007) has pointed out, technology has provided a variety of novel and different means for playing, distinct from those that existed before its advent. McCormick (1987) and Speigel and colleagues (1989) both found that children with disabilities who utilized computer play activities to interact with peers exhibited higher levels of social interaction when compared with play with typical toys; this was especially true for children with more severe disabilities. Software programs have also been developed specifically to help children with disabilities explore the world around them through interactive game play and learning, and parents report satisfaction in being able to see their child play much like their peers (Rose & Meyer, 2002; Tam, Schwellnus, Eaton, Hamdani, Lamont & Chau, 2007).

Tam and colleagues (2007) created an interactive computer entertainment system for children with disabilities with which the child can trigger musical tones by making body movements corresponding with colored shapes on the screen. In trialing the program children ages 30 months to 7 years with cerebral palsy, spinal muscular atrophy, and spinabifida, families reported that not only was the program fun and entertaining for the child, but also served to bring the family closer together by providing a context in which they could play together (Tam et al., 2007). According to a mother who particularly enjoyed the program, "[my son] can't go outside and ride a bike like everyone else; so just to see it bring him such happiness is great...Anything that makes him happy makes me happy" (Tam et al., 2007; p. 105).

Children with disabilities have also utilized robots for a variety of educational and entertainment purposes. In fact, engaging with robots can help young children with disabilities to gain cognitive and social skills in some contexts (Marti, Pollini, Giusti & Gronvall, 2009). In other studies, robots have been shown to be a potentially alternative mechanism for assess the cognitive capabilities of children with disabilities; it has been observed that

children with disabilities can demonstrate higher cognitive levels of functioning when directing a robot rather than completing a standard assessment (Cook, Adams, Volden, Harbottle & Harbottle, 2010). There have also been linguistic improvements noted in children with disabilities who interacted with robots rather than those who participated in only a teacher-directed activity (Lehrer, Harckham, Archer & Pruzek, 1986). Robot play also offers opportunities for choice and control of tasks that the child may otherwise be unable to complete due to limitations associated with his or her disability.

In Europe, in efforts to provide more normative and accessible play opportunities for children with disabilities, cities have begun installing computer based play centers for this population (Brodin, 2000). These play centers provide computerized games as well as digital creative software and other programs to allow children with disabilities to enjoy a greater range of play opportunities (Brodin, 2000). Although families who utilize the play centers relay primarily positive feedback, some parents have requested increased creative opportunities within the play centers, perhaps using items such as scanners or digital cameras (Lindstrand & Brodin, 2004). Critics of the centers have suggested that although the initiative seemed to be successful, some felt that efforts should be directed more towards providing this diverse types of play activities in the child's natural contexts, such as the home and school (Besio, 2002).

Children with disabilities utilize technology to achieve a variety of goals, improve skills in domains of functioning, interact with family and friends, and to play in the way that children were meant to play. Some technology is assistive, some is augmentative in terms of communication, some can be difficult to use, but some can transform the life of the child with a disability by helping them to enjoy normative relationships with the family and social worlds. Children with disabilities, however, are not the only children who are hampered from participating in daily activities with peers and family members; many children with chronic illnesses experience lengthy and repetitive hospitalizations that remove them from these areas often for prolonged periods of time. There are some differences in how

children with disabilities experience and use technology versus how children with serious illnesses and their parents utilize technology. The next section discusses the parent and child with chronic illness are impacted by technology.

Implications

Technology has revolutionized the way we think, the way we interact, the ways we learn, explore, grow, and connect. As computer availability and technology has increased among children and teens this trend has filtered into parenting and education. Technology (e.g., the Internet) has provided a platform or resources and information for parents and educators. Specifically for those who are parents, educators, clinicians, and administrators of children with disabilities, technology offers knowledge, awareness, resources, and support conveniently accessible. Information and ideas are readily accessible for fostering communication between parents, educators, clinicians, and administrators. This progress is positive, but as with any novel invention, there are issues that need to be overcome.

There are three common difficulties that individual's seeking information and resources regarding children with disabilities encounter:

- knowing where to locate the desired information;
- finding time to identify quality information,
- the more information you have the more question emerge.

It is not uncommon for individuals who have a disability or chronic illness to feel isolated and alone; likewise, it is not uncommon for caretakers or professionals to feel limited in their knowledge and understanding about the best course of action to take. The purpose of this article is to assist individuals who are seeking information, resources, and support about children with disabilities find quality information quickly, and offer several outlets for personal and community support. Having access to this type of information through technology can improve developmental, social, and relational outcomes and experiences for children with disabilities and their families (Lenhart, Simon, & Graziano, 2001; Gross, 2004).

In knowing the importance and potential benefits of

technology for parents of children with disabilities, clinicians, educators, and policymakers have a responsibility to help increase families' awareness of and access to these technologies. Clinicians and educators should remain knowledgeable about the technological resources that families may be accessing, such as informational websites and online parental support groups. With a wealth of data scattering the World Wide Web, it is essential that practitioners help to guide children and parents to the information that is most accurate, helpful, and complete. Educators, then, should work to develop online resources that are family and user-friendly and updated frequently by knowledgeable experts on children with disabilities.

Educational researchers and teachers have noted that internet resources have changed how we acquire and use information. For children it has changed the way they think (i.e., multi-tasking), read (i.e., paperless) and write (i.e., email and text slang). It has had an impact on attention, motivation, and self-regulated learning. Parents and educators debate about the negative impact of technology due to the changes they observe, as compared to their own youth; however according to Baron (2005) middle childhood and adolescence has historically generated "linguistic and behavioral novelty" (p. 30).

Parents also report that the internet is a valuable source of support through communication with other parents of children with disabilities. With this being said, these parents should be supported in their efforts to seek information and support via the internet and encouraged to voice their questions and concerns in a variety of forums so that they can make the most informed and appropriate decisions for their child and the family. Policymakers must advocate for funding to help develop and maintain these online parent-to-parent support programs to help ensure that they remain available to families of children with a variety of disabilities and conditions.

Earlier uses of home computers for young children focused primarily of entertainment software and some educational information, current uses are more diverse and sophisticated. The Internet is now an outlet for distributing and acquiring a broad range of information. However, it is

no secret that there are dangers surrounding the Internet; there is misinformation and scammers that need to be avoided. This article and the internet websites provided may exhibit differing viewpoints but they are secure websites; and are based on contemporary research and personal experiences. It should be up to the individual to determine if the website serves their purpose.

Finally, clinicians must remain knowledgeable about current available assistive technologies, as well as the ways in which these devices could be used for the benefit of the child and family in the home and in social settings. Locating the technology, however, is not enough; children and families often cannot access the devices they need due to financial barriers or unfamiliarity with the device and its operations. It is essential that policymakers advocate for funding to ensure that children and families are able to obtain the technology they need, and that educators and clinicians partner to identify appropriate technological resources and provide the education needed to most effectively incorporate them into the contexts of daily life.

At the end of this paper the authors have provided Internet Websites addresses and a brief description of information offered at that web address. The resources are divided into 4 categories: (i) Government, Policy, and Legal; (ii) Media; (iii) Education and Research; and (iv) Support (Tables 1, 2, 3, and 4). The categories will assist parents, educators, clinicians, and administrators identify the type of information they are seeking with ease. Searches for information, once formally conducted in the library, giving not just scholars, but also those most in need access to

	Government, Policy, or Legal Websites for Information and Resources			
#	Abbreviation	Link to WWW	Description	
1.	IDEA 2004	http://idea.ed.gov/	The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the USA. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities.	
2.	NAEYC	https://www.naeyc. org/	The National Association for the Education of Young Children (NAEYC) is dedicated to improving the well-being of all young children, with particular focus on the quality of educational and developmental services for all children from birth through age 8.	

Table 1. Government, Policy and Legal (ctd...)

3.	NICHCY	http://nichcy.org/	National Dissemination Center for Children with Disabilities. They serve the
			USA as a central source of information on disabilities in infants, toddlers, children, and youth. Find easy-to-read information on IDEA, the law authorizing early intervention services and special education. State Resource Sheets help connect disability agencies and organizations in your state.
4. (Great Schools	thtp://www. greatschools.org/	Has a broad range of developmental domains from preschool to high school. There is a Special Education tab that can connect you to information from Learning Disabilities, Autism, Assistive Technologies, and information regarding Family Support, Health & Development, and Legal Rights & Advocacy.
5.	NLS	http://www.nls.org/ specedat.htm	Neighborhood Legal Services provides a PDF of the National Assistive Technology Advocacy Project.
6.	ATA	http://www.ataccess org/	Alliance for Technology Access promotes the use of technology by children and adults with disabilities and functional limitations. Encourages and facilitates the empowerment of people with disabilities to participate fully in their communities. Offers public education, information and referral, building in community org, & advocacy/policy efforts.
7.	OSEP	http://www2.ed.gov/ about/landing.jhtml	The U.S. Office of Special Education Programs
8.	NIH	http://nih.gov/	National Institutes of Health
	Ţ	able 1. Governme	ent, Policy and Legal

	Media Websites for Info	ormation and Resources
# Abbreviation	on Link to WWW	Description
1. CDM	http://www.child developmentmedia. com/parenting-childrern -with-disabilities.html	Child Development Media is the world's largest collection of videos, books and curricula for child development professionals and parents.
2. San Diego Library	http://www.sandiego. gov/public-library/ pctech/index.shtml	This is the San Diego Public Library. You will find many things that may help you better understand how children use technologies for learning. Understanding about these resources you may be able to help children and you may feel more comfortable working with the teachers and administrators in your child's school.
3. NCiP	http://www2.edc. org/NCIP/	National Center to Improve Practice in Special Education Through Technology, Media, and Materials located at Education Development Center, Inc., was funded by the U.S. Department of Education, Office of Special Education Programs to promote the effective use of technology to enhance educational outcomes for students with sensory, cognitive, physical and social/emotional disabilities.
4. Disability & Technology	http://home.nas.net/ ~galambos/tech.htm	An informative resource website.
5. EC	http://www.netc.org/ earlyconnections/	Early Connections links technology with the way young children learn. Resources and information for parents, educators and care providers.
6. FCDT	http://www.fctd.info/	The Family Center on Technology and Disability.

Table 2. Media Websites for Information and Resources

#	Abbreviation	on Link to WWW	Description
1.	NCDDR	http://www.ncddr.org/	National Center for the Dissemination of Disability Research. Under Quick Links you with find a Disability Subgroup, founded in 2008 You will find evidence-based research newsletters, webcasts, and online workshops on assistive technologies.
2.	ATTO	http://atto.buffalo.edu/	Assistive Technology Training Online Project Provides information on AT applications that help students with disabilities learn in elementary classrooms. There are links to basic information, tutorials, resources, and AT decision-making.
3.	CES	http://ces.uoregon. edu/	Center for Electronic Studies provide information and research about way computer technology can be used to enhance learning.
4.	DREAMMS	http://www.dreamms. org/	Developmental Research for the Effective Advancement of Memory and Motor Skills. Aim is to increase the use o computers, high quality instructional technology, and assistive technologies for children with special needs ir schools, homes and the workplace.
5.	PBS	http://www.pbs.org/ parents/	Public Broadcasting System. Although no geared specifically for children with disorders or illness, this website provides a wealth of information on children's learning and social and emotional development This website has blogs, newsletters, games and a broad range of information or specialissues, health & fitness.
6.	LD online	http://www.ldonline. org/index.php	LD OnLine is a leading website on learning disabilities, learning disorders and differences. Parents and teachers a learning disabled children will find authoritative guidance on attention deficidisorder, ADD/ADHD, dyslexia, dysgraphia dyscalculia, dystonia, reading difficulties speech and related disorders.
7.	CDC	http://www.cdc.gov/	The Centers for Disease Control
8.	ECO	http://www.fpg.unc. edu/~eco/index.cfm	Early Childhood Outcome Center
9.	TACSEI	http://challenging	Technical Assistance Center on Social Emotional Intervention for Young Children
10	. AS	http://www. autismspeaks.org/	Autism Speaks

Table 3. Education and Research Websites for Information and Resources

more information, resources and support (Lenhart, Simon, & Graziano, 2001). Fifty-five percent of nearly 1000 teenagers between 12-17 years old use the Internet for social networking daily (Lenhart & Madden, 2007). According to the U.S Census Bureau (2010), the number of adults seeking information and resources to obtain information for resources, self-growth, and support is rapidly growing approaching 70% of the population.

These are challenging but autonomously free times that we are experiencing; we have adapted to several technological trends throughout the course of history, and

Support Websites for Information and Resources				
# .	Abbreviatio	n Link to WWW	Description	
1.	Closing The Gap	http://www.closing- thegap.com/	An organization that focuses on computer technology for people with special needs through its bi-monthly newspaper, annual international conference and extensive web site.	
2.	LD Resources		A collection of resources on various aspects of learning disabilities with comments from community members. Useful archives and links to other resources.	
3.	eHOW	http://www.ehow.com/	This website provides parents with knowledge regarding children and home & family. There are blogs, videos, a library of information from practical experiences and ideas to research based articles. There are ideas and resources to assist parents solve problems and make decisions.	
	Counseling Center	http://counseling- corner.net/index.html	The Counseling Corner is a practice dedicated to providing a range of therapeutic and counseling services for children, adolescents, young adults, couples, and families in the Orlando and Central Florida Area. For individuals not in the area of this center, this website can provide information regarding treatment; and provide insights about how to seek appropriate treatment in your area.	
5.	NECTAC	http://nectac.org/	The National Early Childhood Technical Assistance Center	
6.	M of D	http://www.marchforb- abies.org/default.aspx	March of Dimes	
7.	ALLIANCE	http://www.pacer.org/	The Technical Assistance ALLIANCE for Parent Centers	
8.	NDSS	http://ndss.org/	The National Down Syndrome Society	
9.	ASA	http://www.autism- society.org/	The Autism Society of America	
10	ES ES	http://www.easterseals. com/site/PageServer? pagename=ntl_ homepage	Easter Seals	
11.	ARC	www.thearc.org	The Arc of the United States	
12	CABF	www.bpkids.org	${\it The Child and Adolescent BiPolar Foundation}$	

Table 4. Support Websites for Information and Resources

we can continue to develop and progress. Technology will continue to shape our thoughts and practices regardless of the subject area. Our youth are at the forefront of technological change and are our future leaders (Lenhart, Madden & Hidin, 2007). Kinder (1991) states that there is a need to frame future research in terms of the impact of specific, individual technologies, and under conditions. Parents, teachers and practitioners should look to the future as an opportunity to address the convergence of different forms of technology and consider how children, parents, and others interact and experience technology as a means of conceptualizing its potential; and the impact of technologies now and in the future. This is of value and importance for children with disabilities, their families, and

those who work in the special needs and special education field. There are an enormous amount of benefits afforded to disabled and chronically ill children, if they are accessible to those who need to know about them.

Conclusion

Technology is by no means a panacea – a cure all – or a magic power. It is, instead, a physical and abstract innovation, a social context, an emporium of knowledge, and a gateway to personal connection. Technology was created by humans in the face of very human needs; human needs, in turn, have carved the niche that technology continues to hold in daily life. Whether developmental, educational, social, medical, or psychological, technology offers opportunities for parents and young children alike to meet the whole gamut of human need.

Parents who are raising children with disabilitie stechnologies make information accessible and social and emotional support readily available. children with chronic illnesses, technology is employed to seek information and garner support, in addition to coordinating community assistance and care, while their children utilize technology to learn about and cope with their illness and treatment. Children with disabilities or chronic illnesses, technology improves developmental outcomes, socialization capabilities, and play possibilities. Technology affords the possibility for parents and young children to tailor it to meet their individual needs, concerns, and interests. It is imperative that academics, service providers, educators, and medical specialists together continue to investigate the impact of technology on parenting young children across the spectrum of abilities and conditions. This, it seems, will fuel the continued development of new technologies, which will shape parenting practices that will then provide sources for further inquiry. The authors have included many quality internet websites as places to begin collecting knowledge about a variety of disabilities and chronic illnesses.

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